

February 2009

Bethesda, MD

Education & Training Subcommittee Report

UPDATES

- NNSGRC
 - GEMS database up – links being established
- Regional Collaboratives
 - 50+ educational & training programs
- Genetic Alliance – education survey
 - “Genomic education a high priority”
 - 5 - Agree
 - 4 - Neither agree or disagree
 - 3 - Disagree

Pediatrics 2008; 121;192-217

- “Advances in NBS....new challenges to PCP, both educationally and in the management of affected infants. PCPs require access to information... collaboration with local, state, and national partners is essential....to optimize the function of the NBS systems”

The Patients View

- 70-80% of patients think we know what we are doing:
 - PCP is their first choice for information on genetic disorders
 - They are confident their PCP could choose the genetic test and interpret results
 - Their PCP would be knowledgeable to answer questions about the test result and the clinical implications
 - AMA 1998

The PCPs View

- 60% of primary care providers feel they are not qualified to recommend, order, or interpret molecular genetic tests

PCP Education

- Partners:
AAP/AAFP/ACOG/NHGRI/NNCGRC
- Focus on PCP roles in NBS:
 - Response to initial out-of-range result
 - ACT Sheets / State NBS Program
 - False out-of-range result
 - Coordinate complete evaluation
 - Provide medical home/coordinate care
 - Educate families, healthcare workers

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PCP Education

- Increasing pervasiveness of genetics in the practice of medicine
- Interpreting genetic test results
 - CDC Workgroup – Ira Lubin
 - RAND Corp project – Maren Scheuner
- Improve genetic literacy in PCP community

Collaboration in Education

- E&T Subcommittee to serve in an advisory capacity to current groups involved in both PCP and public/family education:
 - NHGRI, NNSGRC, Genetic Alliance, NCCRCG, NCHPEG, Academies, and others
 - Avoid duplication / enhance collaboration

PCP Education

▣ NHGRI

- “Developing a Blueprint for Primary Care Physician Education in Genomic Education”
 - June 2009

▣ ACNDNC

- Add a MCH roundtable to NHGRI meeting
- Specific strategies and programs
 - Possible future meeting to pursue “blueprint”

NHGRI – Developing a Blueprint

- Propose a 2 hour roundtable on day two
 - Increase the focus of MCH genetics/genomics
 - Preconceptual/prenatal/neonatal PCPs
 - Build on goals of the meeting:
 - Identify core educational needs in genetics and genomics as defined by primary care communities
 - To propose concrete strategies to take advantage of existing opportunities for genetics/genomics education at various stages of primary care physician education